

Thank you for this opportunity to speak with all of you today. We are here to address concerns with SB 248. Our main concern is with the proposed limits on Attendant Care. I will try to be detailed but brief, explaining as best I can our perspective of the issues.

On November 24, 2004, our whole family - my husband (Keelo), myself (Catherine) and my three children, Jacob, at the time 8 years old, Isaac (4) and Noah (2) - were in a car accident. And although properly restrained for his age in a booster seat, Isaac sustained a severe spinal cord injury that resulted in paralysis.

The technical terminology for Isaac's condition is a *C2 SCI ventilator dependent quadriplegic*. This means that the spinal cord was injured in the cervical (neck area) section of the spine at the number 2 vertebra counting from the head downward (the skull is considered number 1). SCI indicates a Spinal Cord Injury. Ventilator dependent means that he relies on a machine to do his breathing for him, as the brain and spinal cord are what direct the diaphragm to make us breathe. The term quadriplegic means that (quad, meaning 4) all 4 of his appendages, both arms and both legs, are affected by the injury.

Due to the extent of Isaac's injuries he is prescribed 24 hour care by a vent-trained registered nurse. Throughout the last 10+ years I can tell you that this has never happened, due to the unavailability of skilled, licensed and competent nursing staff. Although technically we are not certified, registered, or licensed, my husband and I know more than most RNs when it comes to the care of our son. We were both trained at the University of Michigan in all aspects of Isaac's care. And we are the ones who fill in the gaps in Isaac's prescribed care ... all of the gaps. When Isaac was finally discharged from the hospital to come home after the accident we had no nursing care. Keelo and I *were* the nursing care, splitting the 24 hours of each day into 2 - 12 hour shifts that we worked, alternating shifts. (By this time, almost 3 months after the accident, I had left my job and Keelo had shut down his small business, in order to take care of our son.) Presently, we are still involved in Isaac's nursing care, ourselves working about 80 hours (of the 168 hours in a week) that are not covered by registered nurses. We are compensated a reasonably competitive wage (although still much less than our RNs get paid) for the care that we administer. Since we both left our previous jobs and the fact that the hours we cover are equal to 2 full time positions (40 hours a piece), the care that we give is now our livelihood. It's what pays the bills. The reduced Attendant Care benefits proposed by SB 248 would harshly affect our family's already fragile financial stability and detrimentally affect Isaac's quality of life.

SB 248 states that for attendant care provided in the home by a family or household member, payment would be limited to \$15 per hour, REGARDLESS OF THE LEVEL OF CARE. Isaac requires one of the highest levels of care available, one that requires special training above what typical medical staff are educated in. The nurses that take care of Isaac should be at the top of the pay scale for nursing staff. Keelo and I receive a fair wage, however, far below the pay scale of our nursing staff, despite performing the same work and with years of first hand experience. We do not get paid an exorbitant amount for the work that we do. In fact, by us working the hours that would

normally be filled by a vent-trained RN, we are saving the insurance company a ton of money due to the fact that we get paid about half of what an RN would normally get paid. And our rate of pay has not increased one penny in the last 7 years. How many people haven't gotten a raise in 7 years? What I'm trying to say is that our pay is reasonable for the work that we do. It saves the insurance company money. And a cap of this magnitude on Attendant Care benefits would detrimentally affect our family and many others like ours that are just trying to keep our loved ones healthy and well-cared for after tragedy has turned our lives upside-down.

Another troubling aspect is the fact that SB 248 states that the \$15 per hour limit would apply regardless of whether the family or household member was licensed or otherwise authorized to provide attendant care. So if I was an RN previous to our car accident or went back to school now to get my nursing degree, despite my having a license and the education to provide specialized care, which would typically warrant a higher wage, I would still be subject to the pay limit because I'm family. What is the reasoning here?

Now, the limits on Attendant Care for 24 hours per day sounds reasonable on the surface, after all there's only 24 hours in a day, but for an adult patient, such as Isaac will be in the future, who needs *more than one* attendant to accomplish daily care activities, the limit would not suffice. If you have 2 people scheduled to work the same 24 hour period, that equals for the sake of compensation, 48 total hours. The 24 hour a day limit for caregivers, family or not, is inadequate in meeting some patients' needs, would severely limit their care and as a result their quality of life.

SB 248 also seems to offer a possibility of raising the aforementioned limits on Attendant Care rates and hours with a medical review process. However, it is my opinion that much more clarification is needed here to truly offer any guarantee of good faith decisions in this area and safeguards for patients. Having dealt with insurance companies on no-fault issues related to Isaac's care for the past 10+ years if these medical reviews are at the discretion of insurance companies and their associated doctors the outcomes to determine the care and treatment requirements of the patient will rarely be decided in the patient's favor or their best interest.

In conclusion, I would just like to say that today Isaac is thriving. But, should SB 248 be passed as currently written with Attendant Care benefits as stated, things will definitely change for our family, and not for the better. Isaac was not to blame for the car accident that he was injured in. He had no choice in the matter. He is the true definition of a victim. And in the words of this Committee on Insurance Chair, Rep. Tom Leonard, "Government's #1 duty ... is the protection of it's people, particularly those that are most vulnerable." Well, here is a perfect opportunity to fulfill that duty to Isaac and all the others in Michigan like him.

Sincerely,



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